Evidence-Based Early Detection of Developmental-Behavioral Problems in Primary Care: What to Expect and How to Do It

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ABSTRACT
The goals of this study are to (a) inform clinicians embarking on evidence-based screening initiatives about what to expect when using quality tools, including provision of information on identification rates by age, patient mix, and well-visit uptake, and (b) describe the various implementation methods used by other clinics. Participants were professionals in 79 clinics across 20 U.S. states and elsewhere in North America, collectively serving 20,941 families via a Web-based screening service, PEDS Online, which offers developmental-behavioral/mental health and autism screens with automated scoring, report writing, and a mineable database. Problematic screening results were found in more than 1 out of 5 children, and rates of screening test failures increased with children’s ages. Children screened outside the well-child visit schedule were more likely to have screening test failures. Personnel at 22 of the 79 clinics were either interviewed or observed in person to identify implementation strategies. Clinics, even those serving families with limited education or lack of facility with English, found a variety of ways to make use of online screening services. J Pediatr Health Care. (2014) 1-11.

KEY WORDS
Developmental, behavioral, mental health, autism screening, implementing screens, incidence, well-visit uptake, quality improvement initiatives

The American Academy of Pediatrics (AAP) and the National Association of Pediatric Nurse Practitioners (NAPNAP) have created a number of policy and position statements regarding early detection of developmental-behavioral difficulties, autism spectrum disorders, mental health problems, and motor impairments (AAP, 2006, 2009, 2010; High, 2008; Myers & Johnson, 2007; NAPNAP, 2009, 2011, 2013a, 2013b; Noritz & Murphy, 2013). The rationale, thoroughly grounded in evidence, is that early detection leads to early intervention, and through early intervention, children’s outcomes and families’ well-being are vastly improved (Anderson et al., 2003; Campbell, Ramey, Pungello, Sparling, & Miller-Johnson, 2002; Farran, 2005; Muennig, Schweinhart, Montie, & Neidell, 2009; Reynolds, Temple, Ou, Arteaga, & White, 2011; Reynolds, Temple, White, Ou, & Robertson, 2011; Schweinhart et al., 2005).
In the United States, one in six children have developmental-behavioral problems, including deficits or disorders in language, motor, or pre-academic/academic skills; deficits in intelligence; mental health/behavioral/social-emotional problems; or autism spectrum disorders (Baio, 2008; Boyle et al., 2011). One in four to one in five children have either mild delays or psychosocial risk factors predictive of future difficulties (e.g., housing instability, parental depression, limited parental education, poverty, and parenting behaviors that fail to promote children’s language and academic skills). Psychosocial risk factors are strong predictors of present and future developmental and mental health problems (Simon, Pastor, Avila, & Blumberg, 2013). The majority of these children who are not treated in early childhood experience school failure, drop out before completing high school, are less likely to be employed as adults, are more likely to become teen parents, incur high health care costs, and engage in criminal behavior (Simon et al., 2013; Stevens, 2006). If the problems are identified and treated early through services such as Head Start, parent training, or the Individuals with Disabilities Education Act, outcomes are vastly improved. Research on cost savings to society show that for every $1 spent on early intervention, taxpayers save up to $17 (Anderson et al., 2003; Campbell et al., 2002; Farran, 2005; Muennig et al., 2009; Reynolds et al., 2011; Reynolds et al., 2011; Schweinhart et al., 2005).

Accurate early detection depends on validated, standardized screening measures. When clinicians use poorly constructed measures such as the Denver-II (Glascoe et al., 1992) or informal checklists (e.g., milestones built into age-specific encounter forms, including those in electronic health records), only 30% to 40% of children with problems are identified (Bethell, Reuland, Schor, Abrams, & Haltyn, 2011; Radecki, Sand-Loud, O’Connor, Sharp, & Olson, 2011; Sices, Feudtner, McLaughlin, Drotar, & Williams, 2005). In contrast, when quality tools are administered, identification rates exceed 70% (Guevara et al., 2013; Hix-Small, Marks, Squires, & Nickel, 2007). In addition, providers are more likely to refer children who perform poorly on accurate screens, and families are more likely to follow through with referral recommendations (Cox, Huntington, Saada, Epee-Bounya, & Schonwald, 2010; Guevara et al., 2013; Schonwald, Horan & Huntington, 2009; Schonwald, Huntington, Chan, Risko, & Bridgemohan, 2009).

Although the policies of professional societies are wise, pediatric providers face many implementation challenges, including how to administer screenings, score screenings, advise parents, and write/send reports to referral services—with all such tasks, ideally, completed within the average time frame for well-child visits, which is about 18 minutes nationally (Baron, 2010; Haltyn, Stevens, Larson, & Olson, 2011). Because no Relative Value Units are assigned to professional time, self-administered parent-report tools (with assistance from clinic staff as needed) are particularly efficient. Even more efficient is use of online screening services, with which parents can complete measures; scoring is automated, as are referral letters, parent summary reports, and billing/procedure codes. Despite an average per-patient expense of approximately $2.50, online screening ultimately costs less than paper and pencil screens because it saves at least 30 minutes of professional time (Glascoe, Dehnert, & Poon, 2014).

Even so, implementation of parent-report screens in an online environment requires a consideration of staffing patterns (e.g., availability of skilled nursing); equipment/access (e.g., waiting-room kiosks, computers in examination rooms, electronic parent portals, or paper and pencil in waiting rooms); and patient mix (e.g., circumvention of parental literacy challenges by interview administration and languages spoken/need for interpretation/translation services; Glascoe, Marks, Poon, & Macias, 2013). The central goal of this study is to help prepare clinics interested in implementing evidence-based screening by exemplifying (a) how and when other clinics use quality screens to comply with the policies of professional societies; (b) how children perform on screening tests; and (c) the various ways that clinics administer screening tools online according to staffing, equipment, and patient mix.

**METHODS**

**Participants and Settings**

Of 127 practices administering quality developmental/behavioral screening via an online screening service, 79, reflecting a range of practice types (e.g., private practice and public health centers) were selected for data analysis. Practice selection criteria were: (a) frequent use of screening tools, that is, at least several times per day; (b) use of online screening for at least 1 year; (c) provision of care to families of diverse socioeconomic status and language backgrounds; and (d) willingness of clinicians to respond to e-mailed questions about implement approaches.

Settings included private practices in general pediatrics and family medicine (N = 55, serving 14,698 families); public health departments and community health centers (N = 14, serving 2,847 families); outpatient teaching-hospital continuity clinics (N = 3, serving 1,298 families); and other services such as emergency departments or nonemergent crisis call centers, (N = 7, serving 2,103 families).

Data from all sites was aggregated, and each type of site was assigned a unique code for analysis by setting. Collectively, 20,941 children from birth to 8 years of age were screened. The 79 clinics were located across 20 U.S. states (plus one in Canada and one in Mexico). Electronic health records (EHRs) were in use by more
than 50% of sites, but EHRs were not integrated with Web-based screening services at any of the sites. Instead, clinicians used online screening via a Web browser and copied/pasted results into EHRs, or, in the case of sites without EHRs, they printed results to include in paper charts.

Children screened via inpatient services or subspecialty outpatient clinics (e.g., rehabilitation, development-behavioral, and condition-specific such as neurofibromatosis) and those screened in educational settings were excluded from the study. Institutional Review Board approval was obtained for analysis of anonymized existing data gathered from measures widely used in pediatric care.

**Measurement (Patients)**

**Screening**

All participating clinics used PEDStestOnline ([www.pedstest.com/online](http://www.pedstest.com/online)), through which clinicians could administer one or more of three evidence-based measures complying with AAP/NAPNAP policies on early detection. Collectively, these policies involve (a) eliciting and addressing parents’ concerns (recommended at all well-child visits); (b) measuring milestones in fine motor, gross motor, receptive language, expressive language, self-help, social-emotional/mental health, and preschool/school skills (recommended at all well-child visits); and (c) screening for autism spectrum disorder (recommended at 18 months and again at 24 months).

**PEDStestOnline** provides automated scoring, generating referral letters and take-home parent summary reports (in English or Spanish), and identifies appropriate billing and procedure codes. Also available is a parent-portal through which parents can complete measures before the visit but do not see results. Instead, findings are sent to each clinic or provider. Available measures include Parents’ Evaluation of Developmental Status (PEDS), PEDS: Developmental Milestones (PEDS:DM), and Modified Checklist of Autism in Toddlers (M-CHAT).

PEDS is a 10-question screen validated and standardized through use with more than 37,000 children in the birth to 8-year age range (Glascoe, 2012; 2013). PEDS determines whether children are at (a) high risk for developmental problems (and need further medical screens and/or referrals for special education services); (b) moderate risk for developmental and/or mental health problems (and need further developmental-behavioral/social-emotional or health screening and/or referrals to prevention programs such as Head Start plus monitoring/developmental-behavioral promotion); (c) limited risk but in need of in-office advice; or (d) limited/no risk. PEDS elicits parents' concerns in their own words and enables clinicians to focus visits on topics of interest to parents, and thus it serves as an evidence-based well-child visit planner. PEDS can be administered by interview or by self-report and is available in more than 25 translations (e.g., Spanish, Somali, and Vietnamese).

PEDS:DM is a 6- to 8-item screen for children birth to 8 years that has been validated and standardized through use with more than 1,600 children (Brothers, Glascoe, & Robertshaw, 2008; Glascoe & Robertshaw, 2007). The PEDS:DM measures children’s skills in all domains (fine motor, gross motor, receptive language, expressive language, self-help, social-emotional/mental health, and, for older children, academic skills in reading and math) and is designed to replace with evidence the informal milestones checklists often included in age-specific encounter forms. The PEDS:DM helps clinicians rule out or rule in parents’ concerns and helps promote development via short stories about optimal parenting that parents can read aloud after completing the PEDS:DM screening questions. The measure can be administered by interview, parent self-report, or hands-on by providers and is translated into six languages, including Spanish, Chinese, and Arabic.

M-CHAT is a 23-item narrow-band screen focused solely on identification of autism spectrum disorders. Validated and standardized through use with more than 10,000 children, the M-CHAT can be administered by interview or parent self-report and is available for children 16 to 30 + months of age (Robins, Fein & Barton, 1999). Per recommendations from professional societies and from the M-CHAT authors, this measure is best used only after a broad-band screen is administered (because the M-CHAT will miss most children with more common conditions such as language impairment or intellectual or learning disabilities). By design, PEDStestOnline users cannot use the M-CHAT unless PEDS and/or PEDS:DM are used first. Note that the M-CHAT-R has just been published (see [www.MCHATscreen.com](http://www.MCHATscreen.com) for details), but because it has not yet been translated into Spanish, it was not used in this study.

**Patient demographics**

Although many clinicians or parents entered patient demographic information into the optional fields within PEDStestOnline, some did not. In these cases, U.S. Census Bureau demographic information for each clinic’s ZIP code was used as a proxy for ethnicity, parents’ level of education, languages spoken, and poverty levels ([www.census.gov](http://www.census.gov) and [www.brainyzip.com](http://www.brainyzip.com), accessed March 2014).

**Measurement (Practices)**

A random sample of 22 (out of the 79) practices were scrutinized for implementation strategies via in-person clinic visits and/or by interview (through e-mails or telephone calls). Of the 22 practices, 12 were visited in person and 10 were interviewed via e-mail or telephone.
RESULTS
Demographics
The 20,941 families participating in screening had elevated psychosocial risk factors and were disproportionately poor, ethnic minorities, non-English speaking, and had lower than average high school graduation rates (compared with U.S. Census Bureau population parameters, www.census.gov, accessed March 2014). Of parents, only 69% had completed high school (compared with 84% nationally); 30% had incomes below poverty guidelines (versus 24% nationally); 34% were non-English speaking (compared with 12% nationally); 31% were Latino (compared with 17% nationally); and 50% were White (compared with 70% nationally). The incidence for other ethnicities was similar to Census Bureau data: 13% were African American and 6% were Asian, American Indian, or Pacific Islanders.

Screens Administered and Age of Administration
Figure 1 shows the frequency and type of screening test used across the 0- to 8-year age range. Age in months is shown in the 0- to 3-year age range, and age is shown annually thereafter. PEDS was used at 100% of all visits (N = 20,941), followed by the PEDS:DM at 41% of visits (N = 8,657) and the M-CHAT at 21% of visits (N = 4,476). Use of the M-CHAT spiked around 18 months of age and remained high in the months surrounding 24 months of age, suggesting compliance with recommendations for autism-focused screens at these specific ages. The decreasing numbers of children screened after 3 years of age reflects the known and dwindling trajectory of attendance at well-child visits with older children (Selden, 2006).

Performance Across the Birth to 8-Year Age Span
Given elevated psychosocial risk factors in the study sample, it is not surprising that screening test failure rates were higher than the expected prevalence of 13% to 16% (Boyle et al., 2011). Problematic performance on one or more of the three screens was 22% (N = 4,629/20,941). Of families completing PEDS, 17% were at high or moderate risk for developmental and/ or mental health problems (N = 3,705/20,941). Of those to whom the PEDS:DM was administered, 17% had two or more unmet milestones (N = 1,468/8,657), and 8% of those to whom the M-CHAT was administered received failing scores (N = 399/4,476).

Figure 2 shows the percentage of children with high/ moderate risk scores on PEDS, two or more milestones unmet on the PEDS:DM, and failing scores on the M-CHAT. Visible is the known and predictable increase in delays as children’s age increases (Newacheck et al., 1998). Children 3 years and older were twice as likely to perform poorly on screens than were children in the birth through 2-year age range (odds ratio [OR] = 2.3, 95% confidence interval [CI] = 2.12–2.43, p < .0001). Thus it is particularly unfortunate that attendance at well-child visits drops precipitously at age 3 years and beyond (as shown in Figure 1).

Risk of Children Screened Outside the Well-Child Visit Schedule
Most children (66%; N = 13,859) were screened at ages coinciding with the AAP’s periodicity schedule (±1 month), that is, at approximately 2, 4, 6, 9, 12, 15, 18, 24, 36, 48, 60, 72, and 84 months. Nevertheless, 34% (N = 7,082) were screened between well-child visit ages, indicating substantial use of opportunistic

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**FIGURE 1.** Frequency and types of screening test used by age. PEDS = Parents’ Evaluation of Developmental Status; PEDS:DM = Parents’ Evaluation of Developmental Status: Developmental Milestones; M-CHAT = Modified Checklist of Autism in Toddlers.

screening/surveillance. Interestingly, children screened outside the well-child visit schedule were 1.5 times more likely to perform poorly on one or more screening tests (OR=1.6, 95% CI = 1.50–1.67, p < .0001).

Implementation of Online Screening by Clinics
Via clinic visits and interviews, the following approaches to the use of online screening were found. Staffing patterns unique to each approach are also described.

Parent portal
Parent portals have a number of advantages. Families can complete screens prior to the visit but do not see results. Rather, the results are sent directly to clinicians, which gives them advance notice about whether referrals are needed, along with information about the type of anticipatory guidance and promotion of development that should be provided. Use of parent portals enables care providers to prepare for patient visits by obtaining brochures regarding referral resources and materials that provide parenting guidance, such as specific handouts of topics of interest to families; it also gives care providers time to practice how to explain the results, if necessary.

The PEDS Online parent portal through which parents can complete screens prior to encounters was used by 24 of the 79 clinics that collectively screened 2,086 children (10% of the 20,941). Of the 24 clinics, 15 were private practices and 5 were community or public health clinics. Parents accessing the portal were more likely to be English-speaking (OR = 3.2, 95% CI = 1.61–6.32, p < .0001) Otherwise there were no differences in presence or absence of portal use due to parents’ level of education or poverty level. Of the 24 clinics, 20 clinics used PEDS Online with 56% to 100% of families, while the remaining 4 clinics used PEDS Online less than 35% of the time.

Approaches to portal use. Clinics encouraged families to use the portal in two different ways:

1. Having a waiting room computer kiosk or providing parents with tablet computers at check-in so that families could complete screens in the waiting room on the day of the encounter; or
2. Giving parents an appointment reminder card, including information on how to log in to the PEDS Online Web site together with a request to complete screens before the next scheduled visit.

Uptake on portal use. Of the two approaches, the clinics with the highest uptake on portal usage were those providing computers in the waiting room (56%, N = 1169/2086). The four clinics with lower rates of portal usage (44%, N = 917/2,086) used the appointment reminder approach.

Staffing patterns and portal use. Clinics with computers in waiting rooms often had waiting-room attendants (usually gap year students or retirees paid close to minimum wage) to help parents use computers, probe literacy (by asking if parents preferred assistance), and interview families with limited literacy (e.g., by reading questions aloud). Many of the waiting room attendants were also charged with entertaining children, modeling appropriate adult-child interactions (such as talking to children about their activities), and in many cases implementing Reach and Read, that is, by reading children’s books aloud so that parents could complete screens undisturbed.

Interview
Seven clinics administered PEDS Online exclusively by interview to 16% of all patients in the study sample (N = 3,313/20,941). Clinic types included emergency department/crisis call centers, private practices, and community/public health centers. Interview administrations were more common when families did not speak English (OR = 1.8, 95% CI = 1.01–3.22, p < .05) or had elevated poverty levels (OR = 2.0, 95% CI = 1.11–3.65, p < .02).

Approaches and staffing patterns. Some clinicians, once entering the examination room, preferred to begin with PEDS Online screens by interview, as an opening to the encounter. In these cases providers gave live interviews while recording responses onto the PEDS Online Web site.

For clinics working with non–English-speaking families, the presence of bilingual (most often English-Spanish speaking) staff was common. Bilingual staff were varied in professional backgrounds and included physicians, skilled nurses, medical technicians, and receptionists.

In some clinics, families were scheduled for well-child visit appointments on days when bilingual staff were present. Group well-child visits were reported by one clinic that had limited bilingual staff via a “Spanish (other) Language Day.”

When bilingual staff were not available or when clinics cared for families who spoke neither English nor Spanish, interpretive/translation services were used. Telephone services were the most common method; personnel were provided written translations of PEDS Online measures and then engaged in a three-way call with families and clinic staff, providing back-translation into English. Clinic staff (who were varied in terms of professional backgrounds but most often included skilled nurses) then entered parents’ responses into PEDS Online.
Paper-Pencil in waiting or examination rooms together with PEDS online
The balance of practices (48/79), whether interviewing only a portion of families or making partial use of the parent portal, administered screens by asking parents to complete printed copies of screens in waiting rooms (74% of all families, N = 15,548/20,941). After parents completed measures, responses were entered by clinic staff into PEDS Online to obtain results.

Approaches and Staffing Patterns. In some clinics, clipboards were pre-prepared with printouts of PEDS Online screens, often together with other surveys (such as a checklist of Bright Futures topics, screens for parental depression/psychosocial risk, and the 5-2-1-0 obesity checklist). Receptionists were often charged with disseminating clipboards/measures at check-in.

In several large clinics, receptionists were consumed with patient registration and check-out, and so the medical technician station served as the point for disseminating clipboards/measures (in many clinics, several families were in the medical technician’s room at the same time and thus had at least some time to complete measures while they waited).

Next, skilled nurses positioned at (much more private) nursing stations entered parents’ responses into PEDS Online, offering an interview if forms were incomplete or if evidence of limited literacy was present (e.g., no words written on the PEDS Response Form and skipped questions on other measures). Nurses also often clarified parents’ comments and answers to items and pasted final results into EHRs or printed them out for paper charts.

Measures were sometimes (more frequently in clinics) completed in examination rooms, in which case nurses or other staff accompanied families into examination rooms, helped them finish partially completed forms, gathered responses by interview or on paper, entered results into PEDS Online, and also gathered vital health information. In these cases, computers in the examination room were often available (or were brought in by staff), EHRs were in use, and staff often left the EHR age-specific encounter form open alongside the PEDS Online Web site showing results. In clinics without EHRs, staff entering examination rooms, most often nurses, ensured that paper and pencil forms were complete, and then left the examination room with screening test forms to enter information and to print out results to attach to paper charts.

Hands-On screening
Some providers preferred to directly administer PEDS:DM items to children. Although this approach was rare, teaching hospital clinics and practices working with medical and nursing students reported using this approach to ensure that trainees mastered skills in behavior management and learned critical milestones. Although not represented in this study, by report, many early intervention intake services, developmental-behavioral clinics, and subspecialty clinics also used hands-on administration for training purposes, to gain more detailed insight into children’s challenges, and to meet program/measurement requirements.

Gated screening
A few practices used a gated screening process wherein PEDS Online was used as the front-line series of screens. Children performing poorly were then seen by a nurse practitioner or developmental specialist for additional assessment. Measures included the Brigance Screens (Brigance, 2014) and the PEDS:DM Assessment Level (Glascoe & Robertson, 2007). A few sites used the Denver-II, although this measure has limited accuracy and should be avoided, especially when clinics train young professionals and should set an evidence-based example (Glascoe et al., 1992).

DISCUSSION
The results of this study will help clinicians know what to expect from an evidence-based screening initiative: (a) more than one out of five children can be expected to fail screening tests, at least in a sample serving families at elevated psychosocial risk; (b) the risk of failing screening tests increases with children’s age; (c) children are less likely to attend well-child visits the older they are; and (d) children who do not arrive within 1 month of the well-child visit schedule are more likely to perform poorly on screening tests. These results speak to the AAP (2006) policy statement endorsed by NAPNAP that recommends evidence-based early detection, not only at specific ages (e.g., 9, 18, 24, 30, 36, and 48 months) but as “a pattern and practice of attention to development that can and should continue beyond 3 years of age” (p. 406). The findings offer direction for clinic-level advocacy and for organizational strategies, including:

• Ensuring that children are screened opportunistically, that is, at other encounters when families have not brought children in for well-child visits in a timely manner
• Encouraging families of children 3 years and older to keep well-child visits; strategies might include deploying screening tests over the phone with families who have missed appointments (to address families’ concerns and encourage attendance) or assisting day care and preschool teachers with screening
• Establishing a list of referral resources and collaborative partnerships with these services (to assist with follow-up, enrollment, and information sharing between referral services and primary care clinics)
This study also shows that a Web-based screening service can be effectively deployed even when parents have limited education or do not speak English. The various clinics in this study devised a range of approaches to implementing online screening that varied by patient mix, staffing patterns, and available equipment. Although this research focused on a single Web-based screening service, PedsOnline, and is limited to 79 practices embracing four broad types of settings serving pediatric patients, the implementation strategies should be applicable to other clinics using other online services such as ASO Online, CHADIS, and Brigance Screens Online. Directions for future research might focus on different online services, as well as different settings where young children might be screened (e.g., the Special Supplemental Nutrition Program for Women, Infants, and Children and day care centers).

Online screening services are valuable not only because of the substantial time/cost savings that result from automated scoring and report writing but also because online screening enables clinics to scrutinize their own trajectories in early detection. Nurse practitioners are charged with quality improvement initiatives (NAPNAP, 2013b). The availability of an automatically generated database of screening test results (such as the one used in this study) facilitates ongoing appraisal of clinic-level improvements in early detection and how to best address families’ needs for referrals and/or developmental behavioral promotion.

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### REFERENCES


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